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2018-12-02

Molander , P , Jussila , A , Toivonen , T , Makkeli , P , Alho , A & Kolho , K-L 2018 , ' The impacts of an inflammatory bowel disease nurse specialist on the quality of care and costs in Finland ' , Scandinavian Journal of Gastroenterology , vol. 53 , no. 12 , pp. 1463-1468 . <https://doi.org/10.1080/00365273.2018.1541477>

<http://hdl.handle.net/10138/311894>

<https://doi.org/10.1080/00365521.2018.1541477>

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The impacts of an inflammatory bowel disease nurse specialist on the quality of care and costs in Finland

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Supplemental data for this article can be accessed <https://doi.org/10.1080/00365521.2018.1541477>.

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ABSTRACT

Abstract:

Introduction: A specialized inflammatory bowel disease (IBD) nurse is considered a valuable and cost-effective member of a multidisciplinary team, not all clinics responsible for IBD care employ such nurses. We evaluated IBD nurse resources, quality of care and cost effects on IBD patients care in a nationwide study in Finland.

Methods: A healthcare professional electronic survey was conducted in order to assess the impact of an IBD nurse on the quality of care. To study the cost effects, we obtained nationwide comprehensive data covering years between 2008 and 2016 from major administrative healthcare districts of Finland. Patients with a diagnosis of IBD (ICD-code K50 or K51) were identified from the data and their personal contacts and hospitalization were analyzed. The results were compared between healthcare districts with an IBD nurse and healthcare districts without an IBD nurse.

Results: Forty-nine physicians and 88 nurses responded to the survey. Of the physicians, 92% reported that an established IBD nurse had released physician's resources. The most important IBD nurse contributions listed were patient support and follow-up (79–81% of the respondents).

Healthcare district, which had an established IBD nurse, produced more patient contacts. A larger proportion of the contacts was managed by the IBD nurse. Clinics with an IBD nurse reported less patient hospitalization (4–9% vs 11–19%, $p < .001$). Estimated annual cost savings while employing an IBD nurse may be significant.

Conclusion: The introduction of an IBD nurse led to better quality of care and potentially significant cost savings by reducing hospitalization rates and reallocating physician's time resources.

KEYWORDS Crohn's disease; IBD nurse; cost effects; ulcerative colitis

Introduction

Inflammatory bowel diseases (IBD), Crohn's disease (CD), ulcerative colitis (UC) and IBD unclassified (IBDU), are chronic inflammatory diseases that require long-term outpatient follow-up. Disease activity often fluctuates from remission to relapse and can impact upon growth and development, psychological health, social life, education, employment, fertility and pregnancy. In day-to-day clinical practice it is a significant challenge to provide IBD care that fulfills patients' clinical and emotional needs.

Contemporary management of IBD patients requires a multidisciplinary approach that provides a better level of care and improves outcomes [1,2]. Among this multidisciplinary team, the role of IBD nurse is expected to be particularly important in access for education, advice and support. The Nurses-European Crohn's & Colitis Organization (N-ECCO) consensus statements addressed that a specialized IBD nurses should be able to give advice and education not only for

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patients but also for their families to develop an understanding of the disease and treatment strategies [3]. The IBD nurse may also be a moderator between the patient, their family, and the healthcare providers such as gastroenterologist, surgeon, rheumatologist, dermatologist, psychiatrist, stoma nurse, dieticians and general practitioner [4,5]. A nurse who is skilled and competent in the management of IBD can make a significant difference on how well newly diagnosed IBD patients will accept their disease and understand the importance of continuous treatment and follow-up. This may also lead to an improved recognizing of the disease flares, which may reduce the number of both outpatient visits and emergency room visits [6]. N-ECCO survey of nursing practice in caring IBD patients in Europe demonstrated that the role of nurses varies considerably within hospital care, providing complex management and autonomous nursing care [3]. Understandably, both clinical experience and a specific training are required for skilled IBD nurses.

The ECCO (European Crohn's and Colitis Organization) consensus statement recommended already nearly 10 years ago that IBD nurses should be a part of the standard of care for patients with IBD [4]. Regardless, not all clinics responsible for IBD care employ IBD nurses. A recent international survey of 142 adult physicians with an interest in IBD showed that up to 38% of IBD centers are still lacking IBD nurses [6].

Only few studies have been conducted to demonstrate the impact of an IBD nurse position on cost savings in health services, commonly by reducing hospital admission and clinical reviews [7–9]. Most often IBD care is frequently episodic with only few contacts when patient is well and more health care utilization when acute flare occurs. It is complications of IBD that makes IBD costly. On the other hand, employing well trained, a specialized IBD nurse is an additional cost to health care providers.

The current study was designed to evaluate the impact of an IBD nurse on the cost of IBD care in a nationwide study Finland. Furthermore, the most important contributions and challenges for IBD nurses in daily practice were recorded.

Materials and methods

The study comprised two parts as follows: (1) electronic survey addressed to healthcare professional to assess the impact of an IBD nurse on the quality of care, (2) cost effect analysis comparing health care districts with IBD nurse to those without. A healthcare professional electronic survey was conducted by Success Clinic (Helsinki, Finland), revised by three gastroenterologist and one specialized IBD nurse, and carried out between May 2017 and August 2017. The survey comprised questions on available IBD nurse recourses in different health care districts, most common work assignments, challenges and training allowances. The questionnaire sent to the participants can be found as a supplementary file.

The cost effects of an IBD nurse were evaluated by using nationwide healthcare district administrative data. The comprehensive data were available from a population of 1.34 million inhabitants (extracted from eight out of 20 healthcare districts of Finland) covering years between 2008 and 2016 and evaluated by Nordic Healthcare Group (Helsinki, Finland). The final comparison was made by using the data from the year 2016, when the IBD nurse position was stable and comparable in all five healthcare district available. The data were collected only from non-university healthcare districts. The data had been collected with the permission and validated with the representatives of each healthcare district. Patients with a diagnosis of IBD (ICD-code K50 or K51) were identified from the data and their personal contacts and hospitalization in the healthcare districts were analyzed. The results were compared between two groups: healthcare districts with an IBD nurse and healthcare districts without an IBD nurse.

The data comprised all hospitalization and outpatient contacts in the form they were logged in to the medical record systems and included all face-to-face contacts, phone calls, mails and e-mails for a population of 1.34 million. In the contact analyses, the number of contacts which took place in the clinic (face-to-face) was compared to the number of remotely managed contacts (phone calls, mail, e-mail). Additionally, the amount of these different contacts managed by an IBD nurse was compared to the contacts managed by a physician. In the hospitalization analysis, inpatient healthcare utilization was measured by the percentage of hospitalized IBD patients and Two - Proportions z-test was used to calculate statistical significance of the results in the two hospital groups.

Healthcare district 3 was recognized to have established IBD care by an expert working group (including medical professionals with specialized training in gastroenterology) based on a qualitative analysis of the role of IBD nurses and on the district's performance in the quantitative analyses. This healthcare district was chosen to be a reference district when estimating cost savings of IBD care in other healthcare districts. Cost savings were estimated by comparing the

number of contacts and patient hospitalization to the reference district and calculating saving potential in euros. Monetary estimates of the costs of contacts (264 €/per contact at doctor's office, 100 €/per contact at IBD nurse's office and 60 € per non-face-to-face contact) and hospitalization (646 €/per day) were based on the tariff information from South Karelia Social and Health Care District (Eksote) due to information availability and expert assessments of the applicability of the information to the conducted analyses. The costs of employment of an IBD nurse (50,000 €/per year) were estimated with information of average salaries of expert nurses and were validated with the expert working group.

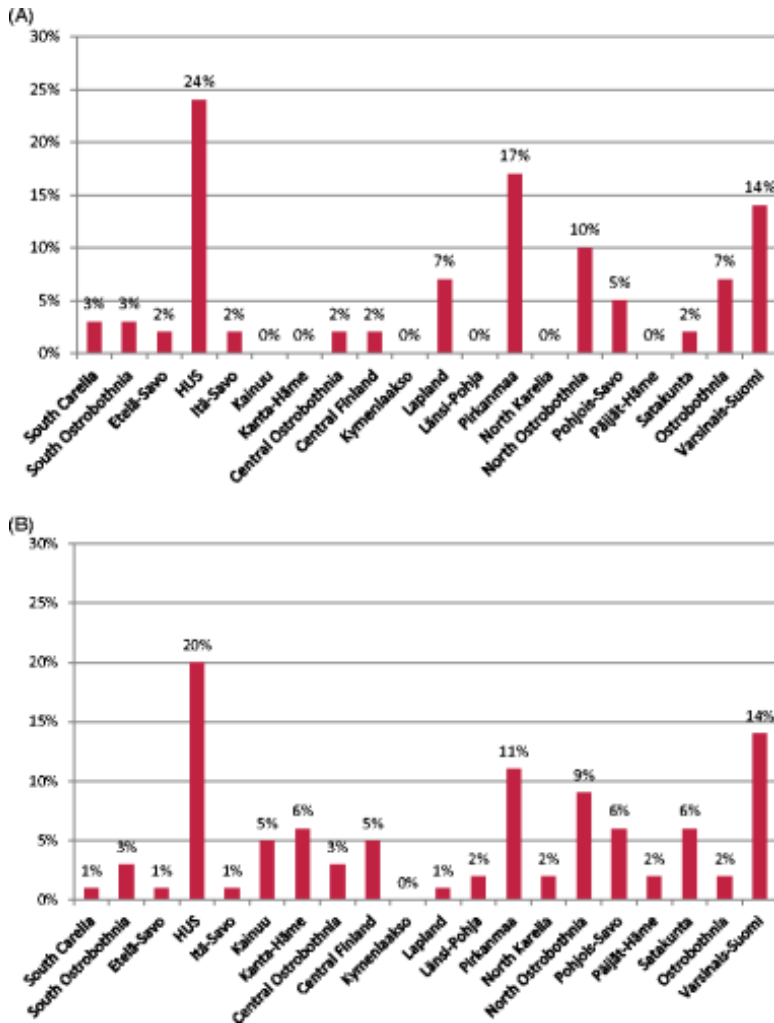
Statistical analysis

To determine whether the difference between two proportions was significant, we used Two-Proportions z -Test. Significance was set at p value less than .05.

Results

In total, 287 electronic questionnaires were sent out. Of these, 42/137 (31%) were returned and filled in by gastroenterologists, pediatric gastroenterologists, internists involved in IBD care and junior doctors specializing in gastroenterology. In addition, 150 electronic questionnaires conducted to nurses were distributed and a total of 66 (44%) nurses, classified as a specialized IBD-nurse, a nurse working at IBD clinic, endoscopic nurse or an occupational health care nurse responded to this survey. One third (26%) of the respondent nurses classified themselves as IBD specialists. Questionnaires were received from most of the Finnish health care districts, see [Figure 1](#). The Hospital district of Helsinki and Uusimaa (HUS), Pirkanmaa and Varsinais-Suomi are the most densely populated healthcare districts and take care of the majority of the IBD patients in Finland. The detailed information on the persons receiving the questionnaire was classified confidential by the vendor.

Figure 1 Physician (A) and Nurse (B) split between health care districts among survey responders. The Hospital district of Helsinki and Uusimaa (HUS), Pirkanmaa and Varsinais-Suomi are the most densely populated health care districts and take care of most of the IBD patients.



All of the respondents were actively involved in IBD care. Among physicians, the median number of face-to-face contacts at the outpatient clinic with IBD patients per week was 12. Nurses reviewed median of 10 patients per week. Of the respondent physicians, 79% performed endoscopies and in most centers (60%) more than 50 new IBD diagnoses were set annually.

IBD nurse resources and professional role

Only half (53%) of the physicians responding to this survey reported to have a specialized IBD nurse in their IBD clinics. On the other hand, up to 20% of the respondent claimed not having IBD nurse resource. Majority of nurses provide IBD care part-time (63%).

The role of the nurse was assessed by evaluating different clinical activities. Most of the contacts performed by nurse were assigned to patient' guidance. Up to 81% of responders provided disease information and support at outpatient clinics personally and 78% by phone. In addition, blood tests screening for toxicity secondary to use of immunomodulators (60%) and taking care of scheduled follow-up visits (30%) were reported as frequent nurse activity. Most nurses reported to have several tasks within IBD nursing. Up to 20% of all nurses consulted physician rarely, but most of the nurses consulted physician in half of the patient contacts or even more frequently.

Unmet needs in IBD care

Both physicians and nurses provided information on unmet needs in IBD nurse resources. The three most frequently mentioned challenges by physicians were: (1) time managements, (2) to complete a specific theoretical and practical training, and (3) to sustain professional skills for caring IBD patients. Nurses' on the other hand pointed out the following: (1) to provide up-to-date knowledge (63%), (2) time managements (63%), and (3) to understand the special situations in IBD care (60%). In open remarks nurses reported the lack of support from the hospital administration to be one of the major challenges. Younger patients at diagnosis, are more likely in need for patient' guidance and close monitoring by trained IBD nurse. Also, web-based monitoring should be provided. Consequently, a common assumption was that well trained IBD nurse may lead IBD care independently and hence liberate physicians' time for other duties.

Non-adherence to medication represents a major issue in patients with IBD [10]. This concern was raised in many nurse survey responses and several reasons for drug non-adherence were identified (multiple answers were allowed): fear of side-effects (67%), overall unwillingness to take the drugs (51%), stopping the drugs in clinical remission (33%), having doubts that the drugs would work (30%), the effect of the drugs were too slow (26%), irregular daily schedule and having problems remembering to take the drugs (25%), problems in communication with the healthcare personnel (20%), cost of the medication (15%) and lack of information and guidance by physicians (9%) or nurses (5%). Several strategies for improving medication adherence were also suggested. Three most frequently suggested strategies were (1) providing better knowledge on IBD treatment (67%), (2) better control of daily living (65%), and (3) educational support on IBD (63%).

Impact on costs

Outpatient healthcare utilization was measured by the number of personal contacts including all face-to-face contacts, phone calls, mail, and e-mails which took place at the outpatient clinic and infusion unit. Those clinics, which had a specialized IBD nurse (Healthcare districts 2, 3, 4, 5 and 6) produced more patient contacts, but a larger proportion of the contacts was managed by IBD nurse and a smaller share was escalated to physician's appointments, [Table 1](#). Also, in clinics with an IBD nurse, a larger proportion of patient were contacted remotely, i.e. by phone or email. Estimated annual cost savings in IBD care ranged between 43,300 and 453,600€ [Table 2](#).

Table 1. Number of hospital care contacts in 2016 per IBD-patient, proportion of nurse contacts and physical contacts. Table Layout

	Total number of contacts per IBD-patient (2016)	Proportion of nurse contacts (2016)	Proportion of physical (face-to-face) contacts (2016)
HCD1	3.40	7.1 %	65 %
HCD2	3.02	21.3 %	52 %
HCD3	5.14	58.2 %	36 %
HCD4	3.67	27.4 %	51 %
HCD5	5.49	20.5 %	47 %
HCD6	2.93	–	53 %
HCD7	5.33	8.7 %	53 %
HCD8	2.57	35.9 %	74 %

HCD: Health Care District. Those clinics, which had an established IBD nurse (Healthcare districts 2, 3, 4, 5 and 6) produced more patient contacts, but a larger proportion of patient contacts were managed remotely.

Table 2. Cost savings of an IBD-nurse. Table Layout

HCD	Change in the cost of physician contacts		Cost savings in hospital days	IBD-nurse resource needed (accuracy 0,5)	Employment costs of an IBD-nurse	Cost savings
	Physical contacts	Other contacts				
HCD1	–101 200 €	–11 600 €	–59 400 €	0.5	25 000 €	–147 200 €
HCD2	5 000 €	–21 600 €	–51 700 €	0.5	25 000 €	–43 300 €

HCD: Health Care District. Established IBD –nurse resource can potentially bring up to 450,000 euro annual cost savings.

HCD	Change in the cost of physician contacts		Cost savings in hospital days	IBD-nurse resource needed (accuracy 0,5)	Employment costs of an IBD-nurse	Cost savings
	Physical contacts	Other contacts				
HCD3	-91 300 €	-15 100 €	-57 700 €	0.5	25 000 €	-139 100 €
HCD4	-115 300 €	-52 200 €	-127 600 €	1.0	50 000 €	-245 100 €
HCD5	-177 500 €	-154 900 €	-24 900 €	0.5	25 000 €	-332 300 €
HCD6	-12 400 €	-11 600 €	-124 800 €	0.5	25 000 €	-123 800 €
HCD7	-283 500 €	-66 300 €	-153 800 €	1.0	50 000 €	-453 600 €
HCD8	-89 700 €	21 800 €	-55 700 €	1.0	50 000 €	-73 600 €

HCD: Health Care District. Established IBD –nurse resource can potentially bring up to 450,000 euro annual cost savings.

Inpatient healthcare utilization was measured as a number and proportion of hospitalized IBD patients, and average length of hospitalization period. The proportion of hospitalized patients was lower in clinics with an IBD nurse as compared to those clinics without (4–9% vs 4–19%, respectively, $p < .001$, [Table 3](#)). When using healthcare district 3 as a reference (0.3 patients per 1000 inhabitants), we estimated that the number of hospitalized IBD patients annually would reduce in all but one hospital district, [Table 4](#).

Table 3. Table shows all outpatient visits and days of hospitalization. Table Layout

	IBD-nurse available	Total number of IBD-patient contacts (2016)	Number of hospitalized IBD-patients (2016)	Proportion of hospitalized IBD-patients (2016)	Number of hospital days per 1000 inhabitants (2014–2016 average)
HCD 1	No	378	41	11%	2.1
HCD 2	Yes	735	54	7%	1.6
HCD 3	Yes; IBD-nurse resource established	1075	45	4%	1.5
HCD 4	Yes	1240	79	6%	2.4
HCD 5	Yes	1214	74	6%	1.2
HCD 6	Yes	578	53	9%	2.6
HCD 7	No	768	147	19%	2.1
HCD 8	No	1056	42	4%	1.7

HCD: Health Care District. The proportion of inpatient care of all contacts was significantly lower in those health care districts with an IBD–nurse, than in those without an IBD–nurse.

Table 4. Difference in the number of hospitalized patients over one year, in all health care districts if the number of patients equals that of health care district 3 treatment periods (0.3 patients per 1000 inhabitants). Table Layout

	Potential reduction in the number of hospitalized patients in one year in different health care districts
HCD1	-17 patients
HCD2	-22 patients
HCD3	-1 patient
HCD4	-37 patients
HCD5	7 patients
HCD6	-14 patients
HCD7	-56 patients

HCD: Health Care District. [AQ4](#)

Potential reduction in the number of hospitalized patients in one year in different health care districts	
HCD8	–14 patients
HCD: Health Care District. AQ4	

Discussion

As the burden of IBD is increasing, a growing number of specialized personnel are needed to offer healthcare services, and clinics could meet this need with resourcing to IBD nurses. However, clinics responsible for IBD care are commonly required to justify the need for new resources, as clinics are often under budget cut. Thus, it is critical to communicate hospital administration more closely on the impact of an educated IBD nurse on the quality of care, and on cost savings. This is most likely relevant in other countries as well.

As adherence to medication is known to be one major concern in IBD care, a nurse who is skilled and competent in the management of IBD can affect IBD patients' understanding on their illness and improve adherence to medication and follow-up [6]. Our study revealed, according to nurses, that most often adherence is due to inadequate patient information and support, and this could be provided by a specialized IBD nurse. Furthermore, as IBD is a chronic disease and relapses occur incidentally, it is possible that timely contact to IBD nurse allows early recognition of relapses enabling prompt adjustments in drug therapy and this may improve long-term clinical outcomes. Besides advantages for patients, the IBD nurse also provides a benefit for the physicians through increased outpatient support and closer patient monitoring.

Nearly half of the IBD clinics in Finland don't have IBD nurse resource even though formal IBD education for nurses is available in Finland and trained personnel is available. This observation led to a conclusion that trained IBD nurses are a considerable unused resource that could be readily taken into use, and this would have a strong positive impact on IBD care. Another interesting finding of this survey is that both theoretical and practical advanced training of IBD nurses is considered inadequate and not supported enough by the employers. Therefore, we encourage all the organizations involved in education of IBD nurses to pay attention to further education of IBD nurses.

Like some earlier studies, this study demonstrates that an IBD nurse position in the clinic can potentially bring cost-savings. Clinics with an IBD nurse reported less patient hospitalization and a larger proportion of the contacts were managed by IBD nurse. IBD complications increase the need for hospitalization and this makes IBD care costly. Leach et al. [7] have demonstrated that IBD nurses provide sustained direct cost reductions to healthcare by reducing hospitalization. Similar findings have been presented by Coenen et al. [11]. They showed that during the first year after the introduction of an IBD nurse, it was possible to convert 30 emergency room visits into outpatient visits and another 133 outpatient appointments could be avoided through counseling by phone or e-mail. In addition, nurse-led telephone follow-up systems have been shown to improve outcomes of care in patients with many other diseases, such as hypertension and diabetes [12,13]. By providing an IBD telephone line, a dedicated e-mail address for patients, or in future Web-based interventions or virtual clinics for patients, the IBD nurse is the first point of contact and enables a quick and easy access to advice and care. Coenen et al. conclude that IBD nurse provides an ongoing contribution toward the efficacy of management of IBD patients and as a result facilitates the delivery of good-quality care. Moreover, Sack et al. demonstrated financially and clinically relevant benefits for IBD patients by adopting a chronic care model with the assistance of a specialized IBD nurse coordinating outpatient care. [14]. Our data correspond to these results suggesting that well trained IBD nurse provides considerable annual cost savings (even hundreds of thousands of euros) by reducing hospital attendances and outpatient appointments for physicians. Even, employing an IBD nurse causes additional salary costs, there may be significant net savings in healthcare costs.

Strengths and limitations

This study is one of the first nationwide studies conducted on the quality of IBD care, providing important data on IBD nurse resources and most common challenges in IBD nurses' daily clinical practice. A major criticism is associated with the survey. The number of respondent was low and quite heterogeneous, which reflects the low number of healthcare personnel taking part in IBD care. Additionally, the authors were not aware of the criterion on which the questionnaire was sent out, because the vendor responsible for the execution of the survey classified this information confidential. Furthermore, hospital district administrative data was obtained only from healthcare districts covering about one third of the nation population. No access to medical reports was provided and therefore no data on the history or severity of

the disease was available. Furthermore, there was no data from university hospitals, responsible for the care of most difficult patients, which however makes the data available more comparative. Also, the annual cost-savings were calculated using an average cost on both inpatient care and outpatient visits.

In summary, our study indicates that a specialized IBD nurse may improve patient access to care, liberate physicians' time, and potentially lead to significant cost savings by reducing hospitalization. Hospital resource allocation to specialized IBD nurse who can coordinate outpatient care, leads to net savings in direct health care costs.

Acknowledgement

MSD supported the study in practical matters, but the study sponsor played no role in the study design, data analyses and interpretation, conclusions or decision to write and submit this manuscript. The Success Clinic that performed the electronic survey had either no role in data interpretation, conclusions or decision to write and submit this manuscript. [AQ3](#)

Disclosure statement

PM has received consultancy and lecture fees and travel support from Abbvie, Allergan, AOP Orphan Pharmaceuticals, Ferring, Janssen-Cilag, MSD, Pfizer, Shire, Tillots Pharma, and Takeda. AJ has received lecture fees and travel support from Abbvie, Ferring, Janssen-Cilag, MSD, MEDA, Mylan, Pfizer, Takeda and Tillots Pharma, and consultancy from Abbvie, Janssen-Cilag, MSD, Pfizer, Takeda and Tillots Pharma. TT has received lecture fees and travel support from Abbvie, MSD, Pfizer, and Takeda, and consultancy from MSD. K-LK has received financial support from Pediatric Research Foundation and Helsinki University Hospital Research Fund, consultancy and lecture fees from Abbvie, Ferring, MSD and Tillots Pharma. PaMä and AA are employees of Nordic Health Group. All authors declare no personal conflict of interests.

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